Shining a light on Alport Syndrome

25-27 September 2015
Göttingen, Germany

The 2015 International workshop on Alport Syndrome

An exciting international event designed by people living with Alport Syndrome in partnership with the leading International experts to collaborate on ideas for the future.

- ☐ **Understand the latest findings and new ideas – hearing, kidneys (basic science and treatments), eyes, pharma solutions, clinical trials through access to alliance of national patient registries**
- ☐ **Collaborate with International colleagues in workshops on specific topics, e.g. novel approaches to treatment**
- ☐ **Present your own research or case studies**
- ☐ **Hear patient perspectives**
- ☐ **Network with experts in related fields or related disease areas**
- ☐ **Be part of the future of Alport Syndrome research and treatment**

alport selbsthilfe

ALPORT SYNDROME FOUNDATION
Hope | Action | Support

AIRG
Association pour l'Information et la Recherche sur les maladies Rénales Génétiques
France

אלפורט
ישראל
Alport
Israel

北大医院
尚厚道德
PEKING UNIVERSITY FIRST HOSPITAL .1915.

FEDERG
FEDeration of European patient groups affected by Renal Genetic diseases

alport uk
a brighter future for people living with alport syndrome

Travel and accommodation bursaries available for a limited number of students in return for bringing a poster with some new ideas and input for our discussions.

What to do next...

Application process now open. Simply email your details (name, address, phone number and a short paragraph indicating your specific area of interest) to: research@alport.info **by 30 June 2015**.
In your short paragraph, please indicate your particular activities which justify favourable consideration of you as a participant and contributor to this workshop. This information is important, as it allows the Workshop Organising Committee to make an informed decision when reviewing and accepting applications.

By applying you will receive details of how to register plus updates and information about the agenda.

Outline agenda and outputs

Participants invited to arrive for the morning of Friday 25 September

To encourage open communication, each member of the workshop will need to agree that any information presented at this International workshop on Alport Syndrome, whether in a formal talk, poster session, or discussion, is a private communication from the individual making the contribution and is presented with the restriction that such information is not for public use. Prior to quoting or publishing any such information presented at the workshop in any publication, written or electronic, we will obtain written approval of the contributing member.

Friday morning: groups running in parallel

- ☐ Alport variant group meeting
- ☐ National Alport groups

Friday afternoon: Current work and basic science

- ☐ Information updates (in plenary) from all participants
- ☐ Basic science plenary and posters with panel discussion

Saturday morning – Clinical science

- ☐ Gene therapy
- ☐ New therapeutic targets for Alport Syndrome

Saturday afternoon – Breakout groups

1. Basic science, translational science and gene/chaperone therapy
2. Diagnosis and genetics
3. Standard of care, repurposing therapy, carriers, management of extrarenal symptoms
4. Future therapies, registries, biobanks, clinical trials

Sunday: Recommendations and guidelines

- ☐ Breakout group discussions
- ☐ Prioritization and recommendations

Outputs

- ☐ Your input will directly contribute to a better international standard of care, earlier diagnosis and improved therapy of patients with type IV collagen disease
- ☐ Your personal copy of the Workshop's excerpt of our re-definitions and discussions
- ☐ A strategic plan, including:
    - ☐ Clear list of research priorities and need for funding
    - ☐ Ways to implement Alport research from bench to bedside
    - ☐ New therapeutic targets, attracting future generations of nephrologists, scientists and researchers
- ☐ An alliance of national patient organisations and agreed ways of working together to support clinical trials and how to fund international research

Workshop Organising Committee and key contributors

Scientific Committee

Professor Colin Baigent, MRC Scientist, Hon Consultant in Public Health, Oxford, UK

Professor Constantinos Deltas, University of Cyprus Kallipoleos, Nicosia, Cyprus

Professor Jie Ding, Department of Pediatrics, Peking University First Hospital, Beijing, China

Professor Frances Flinter, Consultant in Clinical Genetics, Guy's Hospital, London, UK

Dr Daniel Gale, UCL Centre for Nephrology, London, UK

Professor Oliver Gross, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany

Dr Laurence Heidet, Necker Hospital, Paris, France

Professor Clifford Kashtan, Department of Pediatrics, University of Minnesota, USA

Professor Bertrand Knebelman, Necker Hospital, Paris, France

Dr Rachel Lennon, Wellcome Trust Centre for Cell-Matrix Research, University of Manchester, UK

Associate Professor Julian Midgley, Department of Paediatrics, Alberta Children's Hospital, Canada

Professor Jeffrey Miner, Washington University in St. Louis, USA

Dr Laura Perin, Saban Research Institute, University of Southern California, USA

Professor Judith Savige, University of Melbourne, Australia

Dr Judy Taylor, Consultant Paediatric Nephrologist, Evelina Children's Hospital, London, UK

Professor Neil Turner, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK

Representatives from national Alport organisations

Dave Blatt, Alport Foundation of Australia

Susie Gear and **Jules Skelding**, alport uk

Sharon Lagas, Alport Syndrome Foundation, USA

Daniel Renault, AIRG France/FEDERG

Julia Schifter, Alport Foundation Israel

Thomas Simon, Alport Selbsthilfe, Germany